

Do pharmacists contribute to patients' management of symptoms suggestive of cancer: a qualitative study

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Keywords

cancer awareness; early cancer symptoms; early detection; early diagnosis; pharmacy

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Abstract (238 words)

Objectives

Limited awareness of cancer symptoms results in patient delay in seeking help, and contributes to delay in diagnosis. Few UK studies have investigated the potential for community pharmacists to facilitate earlier detection of cancer. This study aimed to investigate what actions patients take to manage their early cancer symptoms, to identify the extent of current community pharmacy involvement and to consider the potential role for community pharmacists to facilitate earlier diagnosis.

Methods

Patients diagnosed with lung, colorectal or gastro-oesophageal cancer in the preceding 12 months were identified during clinic visits by consultants. Semi-structured interviews were conducted, audio-recorded, transcribed and thematically analysed, using the Framework Approach.

Key findings

Twenty-five consenting patients were interviewed: two-thirds were male and more than half had lung cancer. Although all had experienced potential cancer symptoms prior to diagnosis, most underestimated seriousness and mis-attributed causation. Symptoms

were managed by lifestyle changes and self-selecting medicines from local shops, supermarkets and pharmacies but without engaging with the pharmacist.

Conclusion

For symptom management, participants self-selected medicines from community pharmacies, but pharmacy staff were rarely involved. Involving community pharmacists or their staff at the point of sale of these medicines might have facilitated earlier cancer diagnosis. Further research is needed to quantify how many patients with symptoms suggestive of cancer present in community pharmacies, and to understand if a pharmacist's role in facilitating symptom management and appraisal of potential cancer symptoms would be acceptable and effective, before developing any interventions.

Keywords: cancer awareness, early detection, early diagnosis, pharmacy, early cancer symptoms

Introduction

Earlier diagnosis of cancer improves performance status (1) and survival rates (2). Patients in the United Kingdom (UK) are diagnosed with more advanced disease than those in other European countries which may partly explain poorer UK survival (3). Delays in diagnosis occur at almost every stage of the cancer journey, but the biggest delay is between patients first noticing symptoms and consulting a GP (4). Evidence shows that patients often experience symptoms for months before a lung cancer diagnosis but don't seek medical attention (5). This delay is considered long enough to have an effect on treatment outcomes (6).

The National Awareness and Early Diagnosis Initiative (NAEDI) aims to reduce cancer mortality and improve cancer survival rates in the UK by promoting early detection (7). People are encouraged to seek early professional advice for "suspicious" symptoms that could be attributed to cancer (7). However, public awareness of these, and risk factors associated with cancer, is low (8-12). Some studies have proposed that more patient support in primary care, education about symptoms and research into patients' self-management of symptoms could facilitate earlier presentation, prompt referral, and earlier diagnosis, potentially improving cancer outcomes (5,6).

Most cancers produce early symptoms which are often mild, mimic minor illness and are self-treated using non-prescribed remedies (13). Lung and colorectal cancers, two of the three most common cancers in Scotland, account for 27% and 18% of all cancer deaths respectively (14). These cancers have early symptoms (cough and changes in bowel habits/ rectal pain respectively) which could be associated with less serious conditions, and for which patients often seek advice and treatment from community pharmacy.

Approximately 90% of the UK population visits a community pharmacy annually (15), and patients value the self-care counselling they receive from pharmacists (16,17). However, there is limited UK research examining the contribution of community pharmacists to the early detection of cancer.

In November 2010, The Royal Pharmaceutical Society of Great Britain (RPSGB) and the Roy Castle Lung Cancer Foundation (RCLCF) conducted an audit of the number of people with symptoms suggestive of lung cancer identified by community pharmacy staff (18). The following year the audit was repeated targeting colorectal cancer (19). These audits demonstrated that people, with signs and symptoms suggestive of lung or colorectal cancer, were presenting to community pharmacies and that pharmacists were able to advise these patients to seek medical attention, based on the type and number of presenting symptoms. However, referred patients were not followed up to establish if they attended a medical appointment and/or were subsequently diagnosed with cancer. Earlier research in America, investigating pharmacists' ability to identify cancer signs and symptoms found that the majority of pharmacists were confident in their ability to identify symptoms of skin, breast and colorectal cancer but were less confident regarding other cancers. The participants rated further education on cancer symptoms as important. The researchers concluded that pharmacists could have an important role in early detection and prevention of cancer, but further education and evaluation of the impact of this on patient referrals and subsequent cancer diagnosis was necessary (20).

In summary, current evidence suggests there is a need to raise general public awareness of cancer symptoms, to expedite earlier GP consultations amongst those with such symptoms. This paper reports on the qualitative phase of a larger programme of work and focuses on three types of cancer: lung, gastro-oesophageal and colorectal, since their early symptoms are often self-managed through community pharmacy. The aim was to

investigate what actions patients take to manage their early cancer symptoms, to identify the extent of current community pharmacy involvement and to consider the potential role for community pharmacists to facilitate appropriate management and appraisal of potential early cancer symptoms.

Materials and Methods

Study design, setting and participants

A single qualitative, interview-based study was conducted with patients recruited from cancer outpatient clinics at Aberdeen Royal Infirmary, between January and August 2012. Participants were over 17 years of age, had received a diagnosis of gastro-oesophageal (GO), lung or colorectal cancer in the previous 12 months, and were considered, by their clinician, able to participate in the study and provide informed consent. The target recruitment was estimated at 30 patients: 15 from each of the lung, and gastro-intestinal oncology clinics however, when no new emerging themes were identified after two consecutive interviews (data saturation) no further interviews were conducted.

Participant identification and recruitment

Consecutive eligible patients were identified by the responsible clinician during outpatient clinics over an eight-month period and were given a study information pack. With their permission, they were referred to FN (a female pharmacist researcher, undertaking a PhD and with five years research experience) who was present in the clinic and was previously unknown to them. FN described the study, and recorded the contact details of patients interested in participating. FN contacted patients one week later to obtain their verbal consent to participate and arrange a time for their one-to-one interview. Those declining consent were not contacted again.

Written consent was obtained immediately prior to conducting the face-to-face, audio-recorded, interviews (30-60 mins long), which were conducted at a mutually convenient site (home or university) by FN.. A pre-piloted, semi-structured, topic guide (see supplementary material), informed by the literature (4,6,8,10,12,21-25), was used to establish the participant's awareness, experience and assessment of their cancer symptoms, and obtain basic demographic information . The topic guide explored participants' actions to manage their symptoms, including any community pharmacy involvement.

A *Landmark Calendar Instrument* (26-28), was used to aid participants' recall of symptoms and time frames. Symptom lists for the three cancers were developed from published sources (29-36) and were used at interview as prompts to identify symptoms participants may have experienced but had not attributed to their cancer.

Data analysis and reporting

Interview recordings were transcribed verbatim by FN, and a 10% (n=3) random sample was independently checked for transcription accuracy by TP. Transcripts were anonymised; participants were identified only by a unique ID number, their sex, age and cancer type.

Data was stored and managed using Nvivo 9 (37). Content analysis was conducted using The Framework Approach (38). A coding framework was developed by FN and independently validated by all members of the research team. The framework was iteratively revised as new themes emerged. All transcripts were coded by one person (FN), and a 10% (n=3) random sample of coded transcripts was independently double coded by TP to check coding accuracy and consistency.

A thematic framework (**Error! Reference source not found.**) was developed based on emergent key themes which were then synthesised into broader concepts. Recruitment, interviewing, transcription and analysis were carried out simultaneously. Direct quotes from transcripts are presented in Table 2 and assigned to the appropriate participant using the following identification format: [Male/Female, Age band, Cancer Type].

Approval to undertake the project was granted by the North of Scotland Research Ethics Committee (1) 11/ NS/0028 on 27th October 2011.

Results

Participant characteristics

Of the 35 patients contacted by the researcher, eight were too unwell or declined to participate, 25 were interviewed before data saturation was achieved and recruitment was stopped and the remaining two were thanked for their interest but were not interviewed. Participant characteristics are summarised in Table 3. There was no suggestion of any influence of age or gender across the different cancer types. The Landmark Calendar revealed the period of longest delay was the time between the participants' first experiencing symptoms and consulting their doctor (patient delay)(21) and varied from zero to 10 months.

Findings are reported under four main concepts: symptoms experience and appraisal; strategies for self-management of symptoms; triggers and barriers to help-seeking behaviour and sources of help.

Symptoms experience and appraisal

Prior to prompting with a symptoms list, participants identified specific 'first' symptoms: breathlessness, lethargy and cough (lung cancer participants); rectal pain

(colorectal cancer participants); and pain or difficulty swallowing (GO cancer participants). However, participants also commonly experienced non-specific symptoms they struggled to define (Quote 1). Lack of energy and tiredness were consistently mentioned, as having most impact on them and their daily activities (Quote 2). A minority of patients were unaware of experiencing any symptoms and cancer was diagnosed incidentally as a result of an unrelated hospital admission or atypical or sudden onset of acute symptoms, for example. one participant reported coughing up blood, another reported leg pain as their first symptom (Quote 3). Another recalled no symptoms at all, but admission to hospital, after falling in the street, resulted in opportunistic detection of lung cancer.

Symptoms impacted on family lives and ability to engage in family celebrations. While family members expressed concern about the participants' symptoms, particularly weight loss, participants frequently reported not being emotionally affected by their symptoms until they worsened and persisted (Quote 4).

There was a widespread lack of awareness of risk factors and 'red-flag symptoms' associated with cancer. Unless participants experienced progressively worsening pain or unexplained bleeding, they did not assess their initial symptoms as serious, dismissing them or associating them with their lifestyle (smoking or eating habits), minor illnesses (piles, cold or indigestion), injuries (pulled muscle, cracked ribs), their age or other pre-existing medical condition (MS, heart conditions) (Quote 5). Some participants did not attribute their symptoms to anything until they were diagnosed and the majority never thought they had cancer (Quote 6).

All participants reported experiencing at least one symptom, when prompted with the relevant symptom list, which they had not attributed to their cancer prior to the

interview. Symptoms most frequently reported were weight loss and tiredness, with breathlessness, cough, loss of appetite and hoarseness also commonly reported.

Strategies for self-management of symptoms

Participants took different actions to manage their initial symptoms: few consulted their doctor, but more than half self-managed their symptoms using over-the-counter medicines purchased from a pharmacy or supermarket, or which they had at home e.g. cough mixtures, lozenges, haemorrhoid treatments, indigestion/reflux remedies and analgesics. Participants who attended a community pharmacy tended to self-select medicines rather than ask for advice: only three participants sought symptom advice from pharmacy staff. Participants did not consistently purchase medicines from the same place, but when they did, frequent purchases of the same medicine were unchallenged (Quote 7).

Some participants implemented lifestyle changes to manage their symptoms, for example, changes to their diet, drinking water to facilitate swallowing, resting or sleeping and a few tried alternative therapies (Quote 8).

However some participants took no medicines or action to manage their symptoms. They thought their symptoms would go away or tried to forget about them and continued on with their daily routine.

Triggers and barriers to help-seeking behaviour

The main triggers for seeking professional help were worsening or unresolved symptoms, new additional symptoms, or an increasing awareness of their symptoms impacting on their normal activities. Participants frequently reported being encouraged to attend their GP by friends/family, but did not always act on this. Occasionally,

previous experience of illness with similar symptoms triggered help-seeking behaviour, however, their attribution of symptoms to their previous illness was incorrect (Quote 9). The main barriers to accessing help were participant related and linked to symptom awareness and appraisal.

Sources of help

Most discussed their symptoms with their immediate family and/ or close friends.

Some participants stated they would go to their GP if they were ill and needed help from a health care professional, but they frequently reported only visiting the doctor when absolutely necessary, and expressed concern about wasting health professionals' time. Others cited lack of faith in their GP practice, attitude of the GP and reception staff, a dislike of hospitals, a dislike of taking medicines, a fear of catching other 'bugs' while in hospital, embarrassment about the symptoms or the area of the body affected, and living in a remote area as barriers to accessing help from their GP (Quote 10).

A few participants chose to visit a pharmacy before seeking help from their GP. Although the majority of these did not speak to counter staff or the pharmacist, the three who asked for a pharmacist's advice were appropriately referred and were happy with the advice and treatment given (Quote 11). Participants were unaware of the advisory role of pharmacists, with most considering the pharmacy role as one of medicines supply. They therefore, had not considered visiting a pharmacy for help (Quote 12). However, some expressed the view that pharmacists had a bigger role in healthcare delivery (Quote 13).

The main barrier to accessing pharmacy support was a lack of awareness that pharmacists were suitably skilled to respond appropriately to their symptoms (Quote 14). Others included perceived lack of privacy, the openness of the premises, the

249 pharmacy being busy, the age and sex of the counter staff and a reluctance to be
250 questioned about their symptoms.

251 Discussion

252 This exploratory interview study found that people with early symptoms of cancer purchase
253 OTC medicines, sometimes from a pharmacy, rarely seeking advice from a pharmacist and
254 with frequent purchases of the same medicine remaining unchallenged. Although, few
255 interviewees sought a pharmacist's advice about their symptoms, those that did were
256 appropriately referred, however there was a general lack of awareness regarding the
257 pharmacist's skills and knowledge or role beyond that of medicines supply; In addition
258 barriers to accessing pharmacy services were identified.

259
260 This study also found that participants demonstrated a lack of knowledge regarding cancer
261 related and 'red-flag' symptoms. This resulted in a failure to both recognise and appraise
262 early cancer symptoms and lead to participants employing a variety of inappropriate
263 strategies and delays in seeking advice from healthcare professionals, and diagnosis. Other
264 strategies for symptom management included discussing their symptoms with their
265 friends/family; and lifestyle changes. New or worsening symptoms, lay advice, or
266 symptoms that interfered with their daily activities, prompted patients to access services
267 and their first choice, when seeking help, was their GP.

268
269 This qualitative study highlights critical points in the patient journey when community
270 pharmacy could have intervened and provides further insights into some of the reasons for
271 patient delay.

272

273 Strengths and Limitations of study

274 **Strengths**

275 This is the first published study to investigate how people with cancer have, or could
276 have, interacted with a community pharmacy in the lead-up to their cancer diagnosis in
277 order to inform a potential role for community pharmacy in earlier diagnosis.

278 The research methods used were robust: participants were recruited by the consultants
279 from clinics rather than community pharmacies to reduce the risk of bias towards regular
280 community pharmacy users; the interview schedule was informed by current literature;
281 interview transcripts were all coded by the same person, eliminating the potential for inter
282 coder variation; participants were unaware the researcher was a pharmacist reducing the
283 risk of bias in interview responses; a recognised robust approach (the Framework
284 Approach) was used to analyse, interpret and synthesise the data; the transcription, coding
285 and data entry were all independently validated and a landmark calendar facilitated
286 participant recall.

287

288 **Limitations**

289 The sample was two thirds male and one third female. The cancers under investigation are more
290 prevalent in males than females, which may explain the apparent over-representation of males in
291 the sample. Since males are less likely to visit community pharmacies (39) this may have impacted
292 on the extent to which our participants had accessed pharmacy services. The population in this
293 study was older so their symptom management behaviour may not reflect that of the overall a
294 population. It is not known how many patients were approached to participate or how many
295 declined to speak to the researcher, because Ethics denied the request for the consultants to
296 complete a tally of clinic patients with this detail.

297

298 Implication for community pharmacy

299 Previously pharmacies were the most common source for OTC medicines (40), however,
300 participants in our study frequently made purchases from supermarkets, and/or repeat
301 purchases from more than one pharmacy, limiting opportunities for pharmacists to interact
302 with patients or for patterns of purchasing to be noted.

303 Medicines deregulation was introduced to increase safe and convenient public access to
304 medicines, and reduce GP workload for managing minor ailments. However, further
305 deregulation means medicines are more widely available. Accessing medicines from non-
306 regulated outlets diminishes the status of medicines to that of commodity items, reinforcing
307 the perception that symptoms treated by these medicines are therefore minor. In this study
308 self-medicating with self-selected OTC medicines at both pharmacies and supermarkets
309 was the most popular strategy for management of early symptoms and represents a missed
310 opportunity for interaction with a healthcare professional. The continued purchase and use
311 of OTC medicines from a variety of sources, removed the opportunity for pharmacists to
312 intervene, provide appropriate advice, facilitate accurate symptom appraisal and reduce
313 inappropriate medicines use, which could potentially have led to earlier referral and
314 diagnosis.

315 Although some participants visited community pharmacies, they rarely sought
316 pharmacist's advice about their symptoms and multiple purchases of the same medicine
317 over a short period of time were unchallenged. This study showed participants lacked
318 awareness of the pharmacist's role, beyond supplying medicines that is, the provision of
319 professional advice and information regarding symptoms without the requirement.
320 Pharmacists and their staff should be more pro-active in engaging patients in discussion

about their symptoms since in this study, those who asked the pharmacist for help were happy with the support they received and acted on their advice. Community pharmacists have been shown to appropriately advise patients presenting at a community pharmacy with potential cancer symptoms, to seek medical attention (18,19). Raising public awareness of the knowledge and advice available from pharmacists, their ability to recognise and appraise symptoms, and make appropriate referrals, could encourage increased pharmacy consultations.

To increase patient consultations with community pharmacists about potential cancer symptoms, identified barriers such as lack of privacy, the pharmacy being busy, the age and sex of the counter staff and a reluctance to be questioned about their symptoms, should be minimised. This could be done by encouraging use of consultation rooms, upskilling dispensing staff to allow pharmacists time to address the patients' needs, improving the communication, questioning and empathic skills of the pharmacy staff and ensuring they are appropriately trained in symptom management and when to refer to the pharmacist. The findings of this study, therefore, have implications for the development of any potential intervention to improve detection of early cancer symptoms.

Other findings in the context of the literature

Our findings, show lack of awareness of symptoms, risk factors, and 'red-flag symptoms' and failure to assess symptoms as those of an illness, contribute to delay. These findings are reflected in the substantial body of evidence established in the published literature (1,8-12,41). The evidence strongly suggests that these are key factors in cancer patients' delayed presentation and that identification of the existence of an illness is a necessary condition

for seeking help. More accurate symptom appraisal may, therefore, expedite GP consultation.

Consistent with published literature (42), our study identified the period of ‘patient delay’ as a potential point in the patient journey to implement effective interventions to promote appropriate help-seeking behaviour. Similarly the help-seeking triggers identified in this study have previously been documented (41,43,44)

Areas for Further Research

This study has identified some interaction with community pharmacy but has also identified a number of missed opportunities where current community pharmacy services could be developed to enable pharmacists and their staff to take a role in the earlier detection of cancer. Developmental research is now required to devise interventions which address the missed opportunities for community pharmacists to facilitate earlier diagnosis of cancer. This research should follow the MRC Framework for developing complex interventions prior to proposing any community pharmacy based intervention.

Conclusion

Despite recent awareness campaigns people still fail to recognise their cancer symptoms, they self-medicate and delay seeking help. In this study many of the participants attended community pharmacies to purchase medicines but did not interact with pharmacist about their symptoms. Those who did interact with the pharmacist were referred and were subsequently diagnosed with cancer confirming appropriateness. Thus, there is potential for more community pharmacist involvement in both advising on symptoms and referring on. However for this to happen patients need to make more use of pharmacists’ skills. Further research is needed prior to developing any intervention.

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369

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495 *Journal of Cancer Care* 2003;12(4):317-326.

Table 1 Thematic Framework	
1. Participant profile	
	1.1 Age band 1.2 Gender 1.3 Type of cancer 1.4 Smoking status 1.5 Drinking status 1.6 Residence 1.7 Perceived personal health status 1.8 Co-morbidities 1.9 Awareness of red flag symptoms or risk factors 1.10 Previous experience of illness
2. Symptom experience and assessment	
	2.1 Experience and description of symptoms 2.2 Impact of symptoms 2.3 Assessment and attribution of symptoms 2.4 Other symptoms identified from lists
3. Strategies for Self- Management of symptoms	
	3.1 Took no action or ignored symptoms 3.2 Self-medication with OTC medicines 3.3 Lifestyle changes 3.4 Discussions with friends and family 3.5 Information gathering 3.6 Alternative therapy
4. Triggers and barriers for other Help-Seeking behaviour	
	4.1 Triggers for other help-seeking behaviour 4.2 Barriers to help-seeking behaviour
5. Contact with healthcare professional	
	5.1 GP 5.2 Hospital 5.3 Pharmacy 5.4 Contact with NHS24 or alternative therapists
6. Timelines	
	6.1 From awareness of initial symptom to first GP appointment 6.2 First GP appointment to first hospital appointment 6.3 First hospital appointment to diagnosis 6.4 Awareness of initial symptom to diagnosis
7. Understanding and feelings about diagnosis and prognosis	
	7.1 Understanding of diagnosis 7.2 Understanding of prognosis 7.3 Feelings about diagnosis and prognosis

Table 2 Participant Quotes

Quote No	Quote	Participant
1	<i>'Basically my symptoms were one of just not feeling 100%.'</i>	Male,60-69,GO cancer
2	<i>'My windows weren't cleaned, my garden wasn't done, the hoovering wasn't done and the dusting wasn't done. Just everyday things that should've been done weren't being done. ... Personal care started to fail, I mean, I've always been an active person. I never sit about. And for me to be lying on the sofa ... Changed me completely.'</i>	Female, 60-69, Lung cancer
3	<i>'I don't think there were any, ... real symptoms. The only symptom was my legs were sore. That's all there was.'</i>	Male, 50-59, Lung cancer
4	<i>'But then I knew after a few weeks of not getting better then that's unnatural. ... so it's very unnatural for me to be ill so much ... by the time I got to the third doctor I was getting really, sort of, disappointed that things weren't being addressed in a ... in a perhaps a more aggressive manner,'</i>	Male, 60-69, GO cancer
5	<i>'Well the results of having been smoking ... I thought the smoking had reduced my lung function. Not necessarily because there was a tumour there, but because people that smoke a lot become short of breath.'</i>	Male, 60-69, Lung cancer
6	<i>'I had no idea why the tiredness was happening... I mean I was still eating, I was still having' a good diet ... I'd no idea what it was. I'd no idea, until I'd got the CT scan and it was diagnosed lung cancer ... It wasn't 'til later on when it was diagnosed and I was told some of the symptoms, that I realised -Well yes I've had that all summer holidays,'</i>	Female, 70-79, Lung cancer
7	<i>'But I was going through too many bottles of it ... When the cough was at its worst I would probably polish off one bottle a day. I'd have the first 'swig' in the morning and then a 'swig' at dinner time, and a really big 'swig' ... basically what was left at night. Then I'd go and get another bottle.'</i>	Male, 60-69, Lung cancer
8	<i>'I was choosing what I would eat because I couldn't take in any meats, I was going for very soft foods ... if I could</i>	Male;40-49;G cancer

	<i>avoid a meal I would at the time because the eating was so painful.'</i>	
9	<i>'No ... until they told me about the brain tumour [secondary to lung cancer], I thought it was going to be a recurrence of the MS.'</i>	Male;60-69; Lung cancer
10	<i>'because we've moved around about, we've had several different Dr's practices, and the one we've currently got is probably the one we've got least confidence in..... it's just probably the reaction to the individual, just doesn't give you a great deal of confidence.'</i>	Male, 60-69, GO cancer
11	<i>' couldn't have been more helpful, neither could've the girl that was serving me, ... she went and got the pharmacist and she came back. So I mean definitely very, very helpful ... I did tell her that I had the cough and things so. And she did say if it didn't help go back to your doctor.'</i>	Female, 70-79, Lung cancer
12	<i>'I just think that ... with something like that if you're going to get it seen to it's best getting it seen to by the proper peoplewell the specialists in the field ... people that know exactly what they're speaking about. Although some pharmacists are very good, I don't think they've a ... vast knowledge of things outside their own field.'</i>	Male, 70-79, Lung cancer
13	<i>'The pharmacists are experienced people and can help and I don't think we use them to the full benefit.'</i>	Female, 70-79, Lung cancer
14	<i>'I'm either well or I go to the doctor...That's it.....you would need to make people aware that they (pharmacists) have the ability and I don't think that we would consider that they have the ability ... So we just go to the doctors.'</i>	Male, 60-69, GO cancer

Table3 Participant Characteristics n(%)		
	n=25	%
Sex		
Male	17	68
Female	8	32
Age		
30-39	1	4
40-49	1	4
50-59	1	4
60-69	12	48
70-79	9	36
80 or Over	1	4
Type of cancer		
Lung	14	56
GO	7	28
Colorectal	4	16
Smoking status		
Smoker	6	24
Ex-smoker	15	60
Non-smoker	4	16
Alcohol status		
Drinks daily	6	24
Drinks occasionally	8	32
Stopped because of illness	4	16
Never drinks	7	28
Residence		
Urban	12	48
Rural	9	36
Suburban	4	16

Supplementary Material-

Topic guide

TOPIC GUIDE INTERVIEW - Understanding patients' self-management of early cancer symptoms and exploring the potential role of community pharmacy in earlier diagnosis.

Participant identification number

A few questions for background information

1. Patient demography (structured)

Gender ***male*** ***female***

Age 18-29 30-39 40-49 50-59 60-69 70-79 80 or over

Smoker ***YES*** ***NO***

If yes, How much

When started

Drinker ***YES*** ***NO***

If yes How much

How often

	INTERVIEW QUESTIONS	PROBING QUESTIONS
1.	What have the doctors told you about your illness?	Primary / secondary
	Using the Personal Landmark Calendar Instrument would you identify some personally important dates using the pen supplied	for example birthdays, anniversaries, holidays etc
	<p>THINKING ABOUT TIME SCALES</p> <p>Would you indicate on the calendar:</p> <p>When you first noticed any changes in your body</p> <p>When you first thought you should discuss these changes with a healthcare professional</p> <p>When you first discussed these changes with your doctor</p> <p>And finally when you were given your diagnosis</p>	<p>Any signs or symptoms</p> <p>e.g. nurse, doctor, pharmacist</p> <p>Investigations- Instigated by ??</p>
2.	Before you were aware of these changes (signs or symptoms) -How would you describe your health?	
3.	Before you experienced these symptoms were you aware of any warning symptoms you should look out for?	Previous experience of cancer- friends family etc
4.	What were the first changes to your body you remember? (see checklist of symptoms for each of the two cancers attached)	Unprompted first Then prompt with symptom list
5.	How did these symptoms affect you? Physically- emotionally	interfere with your normal daily activities? concerned, worried, scared, stressed, anxious, frustrated? Why?
6.	At that point, what did you think might be causing your symptoms?	Why?
7.	Tell me what you did about your symptoms?	e.g. medicines, alternative therapies nothing? Who/ Why? When? Where? How?
8.	Did you speak to any friends or family about your symptoms or how you were feeling?	Why? When? How long had you had the symptoms before speaking to them? Who did you talk to? What did they say/do?

	INTERVIEW QUESTIONS	PROBING QUESTIONS
9.	Did their response influence what you then thought or did about your symptoms?	In what way?
10.	Did you have any contact with healthcare professionals, other than doctors, to help manage your early symptoms?	Who? When? Why? e.g. community pharmacy, nurse, dietician, physiotherapist (pharmacy staff, nhs 24 etc)
11.	If not -why not?	–too busy, other priorities- Didn't think you needed to- Too far away, convenience
12.	Did you have any contact with any alternative therapy providers to help manage your symptoms?	e.g. acupuncturist, herbalist, reiki therapist etc Who? When? Why?
13.	Why did you choose to speak to that healthcare professional or therapist about how you were feeling/ symptoms?	previous experience, convenience, peers, family, friends, cost
If the participant did visit a community Pharmacy		
14.	Did you ask for advice in the pharmacy?	Why? When?
15.	Tell me about your visit(s) to the pharmacy	Information given to staff/pharmacist How did they respond? -What did they ask you? medicines /advice/information/ follow up who you spoke to-the pharmacy staff and /or the pharmacist?
16.	After the visit(s) to the pharmacy what did you do about your symptoms	Pharmacy visit influenced action?
17.	What affect did the interaction with the staff/pharmacist have on you and the management of your symptoms?	Physically, emotionally, Symptom relief?-less worried, more worried
18.	Were you happy with the interaction with the pharmacist/staff?	Why? What was good about it? What was not so good?

	INTERVIEW QUESTIONS	PROBING QUESTIONS
If the participant did NOT visit a community Pharmacy		
19.	Did you ever consider visiting a community pharmacy about your early symptoms?	If yes-What made you change your mind?
20.	Why didn't you use community pharmacy services?	Symptoms not severe, didn't want to bother them, not a priority-other things going on Too far away
21.	At the point when you thought you should discuss these changes with your doctor what did you think was causing your early symptoms/ changes to your body?	How did this make you feel?
22.	What prompted you to seek medical advice from a doctor	Did you decide yourself – Why or did someone else suggest it? A friend, a family member, healthcare professional, therapist Change in symptoms from first experience
23.	Tell me what you did at this point	Why? self-belief in managing symptoms, fear, priorities,
24.	What did you think might be wrong with you?	Did you think you might have cancer? Why?